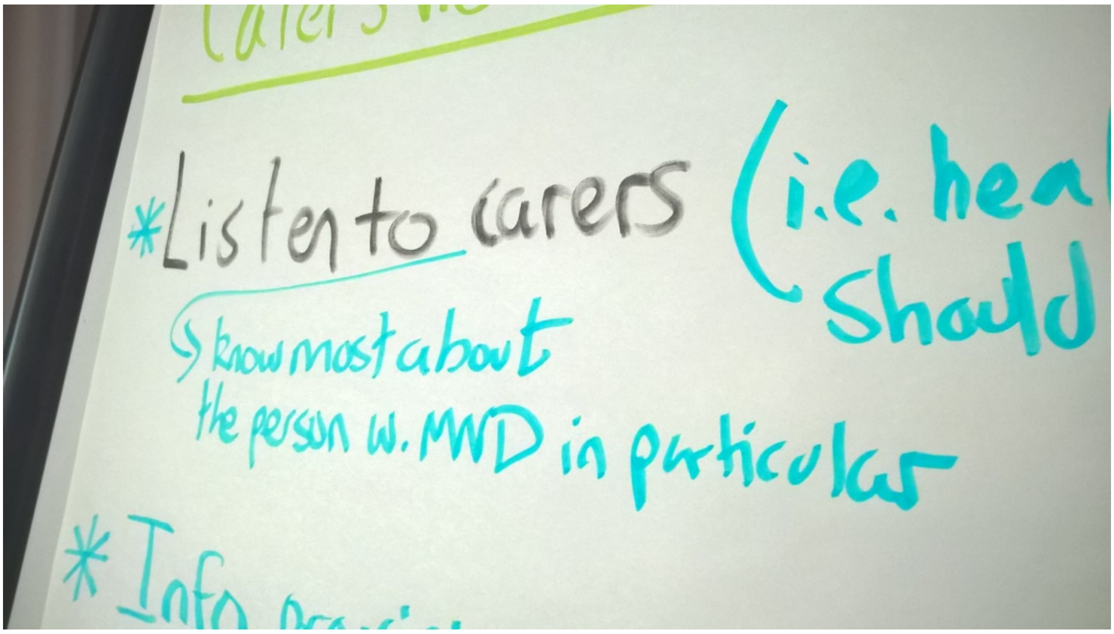
Caring for carers of people with MND: how Government can help



MND Association response to the Department of Health call for evidence on improving support for carers

July 2016

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Executive Summary

Introduction

This report presents the views of carers of people with motor neurone disease (MND), MND Association staff and volunteers on how support for carers needs to be improved. It describes what it is like to care for someone with MND and looks at carers' experiences of support, the financial challenges they face and the extent to which they feel valued and respected for the role they perform.

What is it like to care for someone with MND?

MND is a fatal, rapid and profoundly disabling illness. It occurs when the nerves that control movement within the body die. MND leaves people unable to move, talk, swallow and ultimately breathe. Some people also experience cognitive change or even dementia. More than half of people with MND die within two years of diagnosis. There is no cure.

Caring for someone with MND can be an extremely intense, exhausting and lonely experience. Over half (56%) of carers of people with MND provide over 100 hours of care per week. By comparison, 38% of carers overall provide that level of care.

Tasks performed by carers can include personal care, help moving around inside and outside the home, liaising with health and social care professionals, managing medical interventions like non-invasive ventilation and percutaneous endoscopic gastrostomy (PEG, for feeding) , providing emotional support and support to manage cognitive change, as well as simple day-to-day tasks that people with MND can no longer manage.

Carers tell us that they often experience loneliness and isolation as a result of their caring role. They can also experience a sense of loss of identity, and some report that the relationship with the person they are caring for changes dramatically.

> *I ceased to be his wife – I was referred to as his carer all the time. It's the saddest way that people have to end their marriage.*

Carers' experiences of care and support

Carers identified the following common experiences, both in receiving support to meet their own needs and getting help to arrange care for the person they are caring for:

- **Some carers go without support**
  Carers repeatedly told us that too often health and social care professionals were entirely focussed on the person with MND. Several said they had never been asked about their own wellbeing or whether they could manage the level of care they were expected to provide.
- **Carers aren't getting carers assessments at the right time**
  The MND Association Carers Survey 2015 found that only a third of carers had received an assessment, and 38% were unaware of their right to one. Research by Carers UK found that 39% of people caring for

someone at the end of life waited 6 months or more for a carer's assessment. Lots of carers told us that they didn't feel their carer's assessment had led to anything, or that the support they got was insufficient, inappropriate or irregular.

- **Support and services don't match needs**
  Activities and services aren't always appropriate or accessible for people providing substantial levels of care, or for people of different ages. Carers told us they couldn't make use of groups or services because they couldn't leave the person with MND, and that too often carers did not know what was on offer.
- **There are real problems with respite care**
  Many carers told us that they had no access to respite care. This was either because of concerns about the quality and expertise of care agencies and providers, because it wasn't offered in the first place or simply because there was no availability locally. 46% of carers took no planned breaks from caring, and 42% of those that did relied on family and friends to do so.
- **Children and young people affected by MND need specific support**
  Adult carers told us that they worried about the impact on children and young people of both helping to care for someone with MND and losing a parent, other relative or friend to the illness. Statutory services were not always good at taking the needs of children and young people into account, or at signposting to available support.
- **There is very little support for carers after bereavement**
  Support post-bereavement was either not available at all for carers, was extremely limited or did not come at the right time. Carers talked about being 'dropped' by services after the person with MND had died. This is a serious gap in service provision.
- **Problems in arranging care for people with MND has a significant negative impact on carers**
  Carers described not being listened to or respected by health and social care professionals when it came to trying to get the right care in place for the person with MND. They felt that professionals did not think or plan ahead, and delays in getting care, support and equipment in place put extra pressure on them.

Work, financial support and the cost of caring

We spoke to carers about the financial impact of caring, benefits, the role of work in their lives and difficulties in getting back into work after their caring role had ended. They told us the following:

- **Caring for someone with MND can have a significant impact on earnings, savings and future financial security**
  Carers told us about the impact of having to leave their job or cut back their hours, passing up opportunities for promotion, using up savings and not being able to replace them. There is a stark gap between the financial impact of caring and the economic contribution carers make;

just one person providing at least 100 hours of care per week to someone with MND saves the state more than £89,000 per year.[1]

- **Carer's Allowance is not fit for purpose**
  Carer's Allowance simply does not provide enough financial support. Systems can be overly complicated and bureaucratic. The system does not facilitate transitioning out of or back into work, as caring roles become more demanding or come to an end.
- **Work is very important to some carers, but employers are not always aware of what it means to be a carer**
  Many carers told us that work provides a break from caring, and can help people maintain a sense of normality and identity. Flexible working, where available, is extremely important to enabling carers to stay in work. However, carers also described problems they faced where employers weren't flexible, and problems returning to work after bereavement.

Recognising, valuing and celebrating carers

Carers told us that they did not feel listened to by Government and services. They wanted more work to be done to increase the public's understanding of what it meant to be a carer, and more support to make them feel like they weren't alone. This included promoting and encouraging local peer support groups for carers.

Our recommendations

The report presents a range of recommendations around practical support, financial support and valuing carers. We believe that all of these recommendations should be considered by Government, given the problems with accessing support that carers have described to us.

A full list of recommendations can be found at the end of each section. Below we have identified our top priorities from within this list which we believe would make the biggest difference to carers of people with MND.

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[1] Calculated based on methodology from Carers UK, *Valuing carers 2015*: unit cost of replacement care (£17.20) x 100 hours x 52 weeks.

Our top priorities for improving support for MND carers

1. **Create a universal offer of free, non-means tested support for carers while performing their caring role and after bereavement. This means:**
   - (i) **Ensure every carer gets a carer's assessment at the right time**
     Health and social care professionals must co-produce an action plan for support in partnership with the carer. Carers of people with progressive and terminal illnesses like MND must be fast-tracked for assessments.
   - (ii) **Improve access to respite care**
     Government must conduct a review into the availability, quality and range of respite care and support available across the country, and establish a clear programme for improving access to this.
   - (iii) **Support bereaved carers**
     Create a new programme of work around support for bereaved carers, including young carers, and ensure that post-bereavement support is timely, sensitive and sufficient.

2. **Create a system of financial and employment support that ensures that carers do not experience hardship or poverty as a result of their caring role. This means:**
   - (i) **Introduce a statutory right to carers leave**
     This will provide the support carers need to take a break from work, and help to normalise the caring role in the workplace.
   - (ii) **Make Carer's Allowance work better for carers**
     Increase Carer's Allowance to at least the value of Jobseekers Allowance, and introduce a taper that facilitates carers who need to transition out of work as their caring role increases, and move back into work gradually after bereavement.

3. **Work towards a society where recognising, valuing and supporting carers is everyone's responsibility. This means:**
   - (i) **Ensure everyone is responsible for identifying and supporting carers**
     Create a statutory duty for the NHS to identify carers and put carer needs at the centre of their work.
   - (ii) **Listen to carers**
     Carers' views about support and services available must be listened to and acted upon, and they must be respected as expert partners in care.

1. Introduction

1.1 About MND and the MND Association

Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.

There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and groups, and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

Support for carers provided by the MND Association

The MND Association provides a range of support for carers of people with MND, including:

- Producing a range of information for carers, including *Caring and MND: support for you* and *So, what is MND anyway?*, a guide for young people
- Signposting current and former carers to available support, benefits and care options through the Association website, information sheets and the MND Connect helpline
- Providing local guidance through regional staff and volunteers
- Enabling peer support through local branches and groups and our online forum
- Providing MND Support Grants, Carers' Grants, a young person's grant and equipment loans as appropriate
- Directing carers to opportunities for training in care tasks
- Raising awareness about carers and the demands of MND within regional health and social care systems
- Campaigning and influencing government and health and social care services.

1.2 About this report

This report has been developed in response to the survey and call for evidence on improving support for carers, launched by the Department of Health in March 2016, to help the Department inform the development of a new cross-Governmental Carers Strategy.

Explaining its motivation for developing this strategy, the Department says:

> *We think that we need a new strategy for carers setting out how we can do more. One which reflects their lives now, the health and financial concerns they have, and gives them the support they need to live well whilst caring for a family member or friend.*[2]

The MND Association welcomes this Government's focus on finding better ways to support carers, and we agree that the new strategy should address the very real challenges they face.

This report describes the experience of caring for someone with MND. It highlights the range and intensity of care provided by unpaid carers and the services that should be in place to make their role easier. Carers tell us that caring for their loved ones can be a rewarding role, but also an extremely demanding one. Caring for someone with an often rapidly progressive and terminal illness like MND poses some unique challenges, both while they are living with the disease and after bereavement.

The content of this report reflects the views of current and former carers, MND Association staff and volunteers. It draws on data from the Association's 2015 Carers Survey, which had 452 responses from current and former carers. This sits alongside telephone interviews and focus groups conducted during the Department of Health's consultation period. MND Association volunteers also participated in a joint meeting of the All Party Parliamentary Groups (APPGs) on MND and on Carers during the consultation, and material from both this and a previous APPG on MND meeting on benefits has also been included.

MND presents and progresses in different, often unpredictable, ways for different people. We have tried to capture a range of different experiences within this report. However, participants in one focus group highlighted that both the responses to the Government's survey and the Association's own research will likely capture more views from people who have more time to take part in these activities. Those for whom the caring role is particularly intense, where the person they are caring for has the most rapidly progressing needs and where the carer is receiving the least support may be less able to take part, and may consequently be least represented. We encourage Members of Parliament and officials from across Government who have a role in supporting and valuing carers to meet with this group of carers to understand the impact their caring role has on their lives, and the level and type of support they need.

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[2] Department of Health, *How can we improve support for carers?* (2016)

2. What is it like to care for someone with MND?

In 2015, the MND Association carried out a survey of carers of people with MND.[3] 452 carers and former carers responded. The survey asked a range of questions about carers' experiences of providing care, the tasks they perform, their concerns and the support they receive.

The survey provides a snapshot of what it is like to be an MND carer, including some information about the demography of this group of carers:

- 78% of MND carers are female
- 61% are over the age of 60, and 27% are over the age of 70
- 87% are caring for a husband, wife, civil partner or partner

Other carers told us they had disabilities or health conditions themselves. Some were caring for other parents or children with health and care needs, and others had childcare demands as either parents or grandparents.

More than half (56%) of carers of people with MND provide more than 100 hours of care per week. This is significantly higher than the figure for all carers in England returned by the *Personal Social Services Survey of Adult Carers in England, 2014-15*, which found that 38% of carers provided more than 100 hours of care per week.[4]

The range of tasks performed by an MND carer is significant. The vast majority of carers helped people with MND to attend medical appointments and liaise with professionals (91%), helped with personal care (87%) and with moving around outside the home (87%). 81% of carers provided emotional support, and 76% helped them cope with some form of cognitive change such as changes to mood, behaviour, thinking or memory. Two thirds of respondents said they lifted or hoisted the person, and 67% helped the person they were caring for communicate with other people.

Carers also described carrying out tasks such as helping the person to manage their financial affairs, gardening and house cleaning, shopping and other daily activities. During interviews, carers described having to take over daily tasks that their partners had done, or that had been a joint responsibility.

> *[Before the diagnosis] he was so dependable. He decorated, put floors down, did everything – I'd never put a bin out or paid a bill in my life, it was a shock for me... It's amazing how quickly you can learn when you have to.*
>
> Telephone interview 2

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[3] Sarah Fitzgerald, *Experiences and views of carers of people living with MND* (MND Association: 2015)

[4] Health and Social Care Information Centre (HSCIC), *Personal Social Services Survey of Adult Carers in England, 2014-15* (HSCIC: 2015)

Personal story: living with MND

We have a joke – he says "it's all about me!", and of course it is and it has to be. Everything I do is informed by MND; if we go out together it becomes all about how can we get there, what do we have to take, do we have to bring the ventilator. If I need to go out I can't go unless there's someone with him.

I don't always factor in all the things that have to be done. The shopping, cleaning, the laundry, the ironing – I just try and power through it all. He needs help with everything, whenever he needs something it's you really. That's on top of all those other things. It's awful for him because he has to ask for everything. He's really patient with it. The very last thing on the list is anything for me. I'm much less likely to say "I need to do some writing" or something for myself, that gets shoved to the back. People don't factor in that there's so much involved in looking after someone with MND.

You want it all to be normal – you don't want him sat looking around if the cleaning's not been done or the ironing. There's a certain standard I like things to be at just clean and organised nothing perfect, keeping it on an even keel. The caring role is added on to everything else you're doing. People just see you physically looking after someone, they don't look at all those things that used to be both of us doing, helping things keep ticking over. The longer it goes on the less he cares about that kind of thing. Keeping the garden nice, paying the bills, fixing the roof. The more removed he becomes from those daily troubles – he doesn't want to know about it. You've just got to do everything, that pushes you into a lonely place as well, whereas it was more of a partnership before.

Telephone interview 1

Many carers told us about the sense of loneliness and isolation that they experienced as a result of caring for someone with MND. This can be compounded by a sense of loss of identity or a changing relationship between the carer and the person they are caring for.

> *The first thing I found so shocking is I ceased to be his wife – I was referred to as his carer all the time. It's the saddest way that people have to end their marriage.*
>
> *[As an MND Association Visitor[5]] I sometimes spend longer standing on the doorstep talking to the carer than the patient. My husband would*

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[5] An MND Association Visitor (AV) is a volunteer who will be matched with a person with MND to offer them free and confidential emotional support, and information about the Association and other services that helps people to make informed choices. Find out more here: http://www.mndassociation.org/get-involved/volunteering/association-visitors/the-role-of-association-visitors/

> *have been unhappy because he would have felt excluded, but [as a carer] sometimes that's all you've got.*
>
> Telephone interview 3

> *The loneliness of it – you need someone to talk to, probably someone who's been through it is better. If you go to the hospital and the consultant says it's cancer you've still got hope. When they say MND there is no hope. It's a death sentence. It can be very lonely, MND. You don't really talk to your family because you don't want to stress each other because you all just need to get along with looking after him.*
>
> Telephone interview 2

> *It's become more all consuming. I'm more defined by it now than I was before. There are times when you do get quite resentful – not of him, of the situation. People say oh you have a choice – you don't have a choice. You wouldn't choose to leave, that's not a viable choice. The longer it goes on the more depressing it gets being trapped, but at the same time you know at some point he's going to go. No family carer chooses the role, it's thrust upon you unexpectedly and you take it on.*
>
> *It certainly has affected the relationship – the dynamic has to change because it becomes dependent. It can't be the same. He's conscious he doesn't want to rock the boat with any of the carers but particularly me. Even if he's annoyed with me he knows I still have to take him to the toilet and wipe him – how humiliating when you don't even particularly like the person at the time! There has to be some recognition of the fact that over time it has a huge impact on your sense of self and it's difficult to accept that your life isn't going to go the way you thought it might go.*
>
> Telephone interview 1

As part of the survey, carers were asked how they felt about their caring role. As figure 1 on the following page shows, while carers viewed their caring role as important to them, they also found it challenging and didn't always get the support they needed. Only 39% said they have a good level of emotional support, and only a quarter said they get all the practical support they need.

Finally, carers were asked to list three words that they felt best described how it felt to be a carer. The image below in figure 2 represents common words, with the size of the word proportionate to the number of times it was used by carers. Words such as 'exhausting', 'emotional' and 'lonely' feature commonly, alongside 'rewarding' and 'needed'.

> *Those words are exactly right.*
>
> Focus group participant

Figure 1: responses to the question ‘thinking overall about your caring role, which of the following statements reflect how you feel about it?’

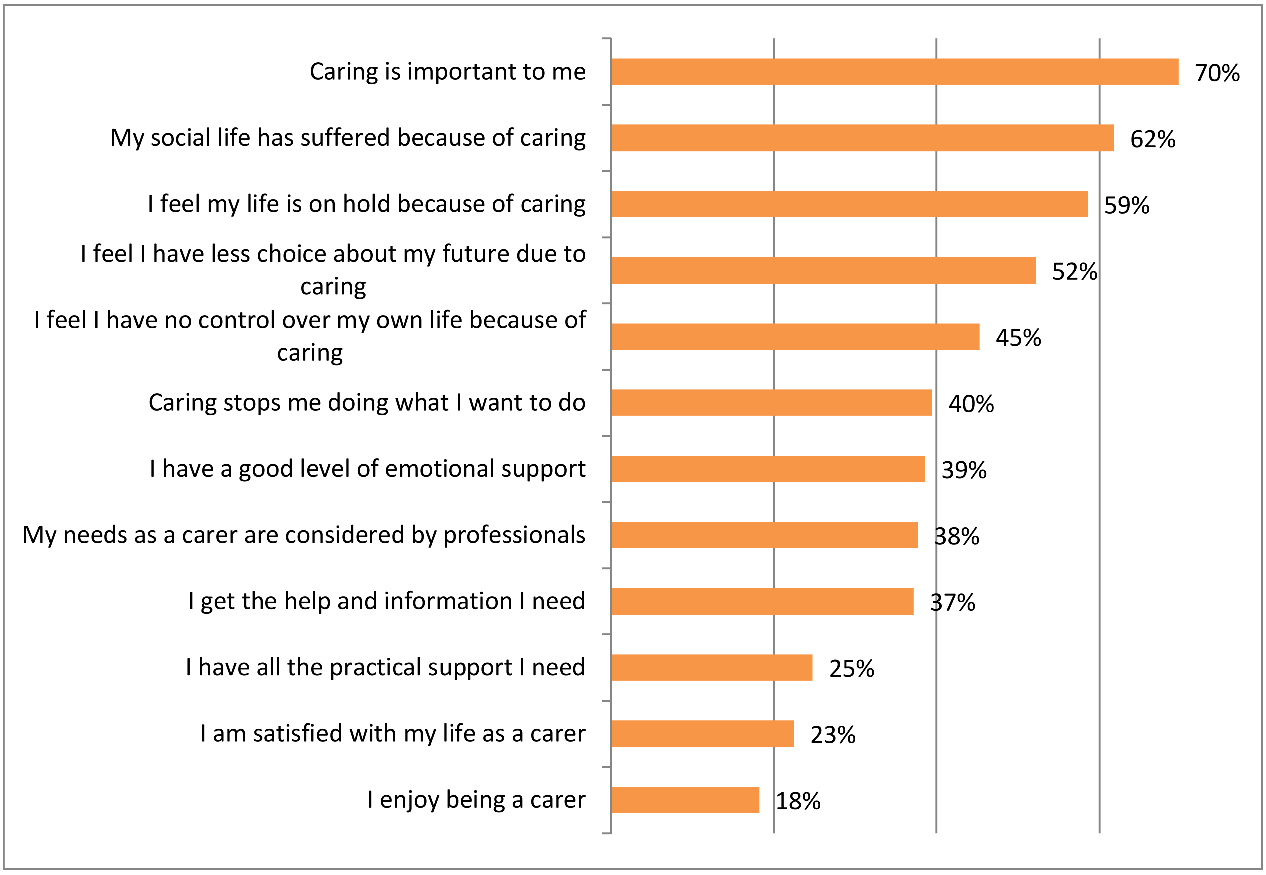

Figure 2: responses to the question ‘please write down three words that you think best describe how it feels to be a carer’

3. Carers' experience of care and support

Throughout the research for this report, carers talked about the support they needed and received, and the care and support available for the person they were caring for. Problems and delays with the latter had a profound impact on the ability of the carer to cope. This report touches on both elements.

3.1 Support for carers

Some MND Carers go without support

A number of carers reported that health and social care professionals focussed entirely on the person with MND. They felt that this left carers with little support and little opportunity to have a conversation about their own health and caring role. Several also mentioned the sheer number of health and social care professionals involved in the care of the person with MND, but the lack of attention paid to their own needs.

> *No healthcare professional has ever in 6 years asked how I am doing.*
>
> MND Association volunteer feedback
>
> *The first person I visited [as an MND Association Visitor] it was clear the wife was crumbling. She had a calendar of professionals coming in but the whole focus was on the person with MND, her needs were neglected.*
>
> *After the diagnosis a plethora of [health and social care professionals] came and visited. The feedback was all about the patient, not about me. No one inquired into my health. There was no assessment.*
>
> Focus group participants
>
> *I am not sure if I have had an assessment or not. We have had a rush of people coming to the house in a short period of time, a little confusing.*
>
> MND Association Carers Survey 2015 respondent
>
> *[After he died] I suddenly began to think about things and got quite angry. Then I found out there was a thing called a carer's assessment, and that I should have had one. I didn't know where that was meant to come from.*
>
> Telephone interview 3

For some former carers, this lack of focus on their own health and wellbeing meant that the extent of the care they were providing without support wasn't recognised at the time, or wasn't recognised quickly enough:

> *I was lifting a 15 stone man, by myself, and they would ask 'do you need any extra help?' and he would say 'no we're fine.' He didn't want to get help because it would be an indication that he was getting worse. If someone had asked me 'are you coping?' it might have been a different answer... [When he was admitted to hospital] they could see what was going on at home and that it wasn't safe. It had to be a crisis before anything changed. In hospital they required three people to move him.*

> *There was a discharge meeting, and they said they would only discharge him if he agreed to have extra carers in the house. I'll never forget, [my husband] capitulated as soon as it was put to him in a professional way.*
>
> Telephone interview 3
>
> *Why is it not until they break down that they get the support they need?*
>
> *I was providing 136 hours of care a week on my own, lifting my wife 40 times a day with no hoists, no support.*
>
> Focus group participants

Carers should not be expected to wait until crisis point before their needs and capability for caring is considered. This risks the health and wellbeing not only of the person with MND but of the carers themselves, which in turn can place unnecessary pressures on acute and emergency services. Health and social care professionals must ensure that carers are properly identified and their needs and ability to care appropriately and sensitively assessed.

Edgehill University has developed a tool called the Carers' Alert Thermometer (CAT), designed to help health and social care professionals identify and meet the needs of carers providing end of life care in the home. The tool asks 10 questions, and asks professionals to rate needs as low, intermediate or high. Questions cover information about the condition the person receiving care has, help to provide physical and emotional care, whether a carer has a named emergency contact, whether they feel listened to and whether they are able to meet their own needs. It also includes a question about the person receiving care's wishes and preferences for end of life. The CAT has an action planning section to help professionals discuss and agree next steps with the carer.

The tool is available free-of-charge, along with more information about the project and its development, here: https://www.edgehill.ac.uk/carers/

Problems with carers' assessments

The MND Association Carers Survey found that only a third of carers of people with MND had received a carer's assessment. 38% were unaware of their right to one.

In addition, research by Carers UK found that 39% of people caring for someone at the end of life waited 6 months or more for a carer's assessment.[6]

Of those who reported that they had received a carer's assessment, 44% were offered equipment. Just under a third (31%) were offered information about funding sources, local services and emergency support. 19% were offered nothing. Many felt they weren't offered sufficient support through statutory services.

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[6] Carers UK, *State of Caring 2016* (2016)

> *Had one assessment at the beginning and never heard anything for the next 7 years.*
>
> *I was promised help but it never materialised.*
>
> *Despite being my husband's full time carer, catering for all his needs from toileting to hoisting, and only being able to leave him for an hour or two at most, I was offered the grand sum of £10.43 per week to allow me one hour of respite care!*
>
> MND Association Carers Survey 2015 respondents
>
> *Recently [my husband's] social worker brought me a form to fill out – I found it so dense and some of the questions didn't make sense, you didn't know what they were asking. That was months ago but I've not heard anything. I haven't found [the support] amazingly helpful and it wasn't [there] at the beginning [after diagnosis]. You need it at the start so you can have a benchmark that you can measure maybe six months later.*
>
> Telephone interview 1

Where carers assessments work well, and result in appropriate support, they can make a significant difference to carers' lives. Some carers said they had received welcome support, in the form of small annual or one-off grants ranging from £75 to £200, respite care, and extra day and night care for the person with MND.

> *Carers Assessments are a great way of sitting down and realising what you are doing. I appreciate mine. I have had two now and the opportunity to speak to someone about my worries, my caring role and what help there is for me is valued. Along with the small grant I receive to make sure I go and do something for myself. This year I went on a day's sewing course. It was lovely just sewing for a few hours.*
>
> MND Association volunteer and current carer
>
> *[The local] carers group offered me six months of counselling – she was excellent. I found it difficult but that was because she was so good. It was so completely focussed on me. She would ask me a question – she was so insightful – it would go right to the heart of me. That was a number of years ago now. It probably was as a result of that first assessment.*
>
> Telephone interview 1

However, the evidence strongly suggests that good practice is not consistent.

This situation is clearly not acceptable. The Care Act 2014 introduced some vital new rights for carers, but we are concerned that these are not being met consistently across the country. Research by Carers Trust supports this concern. It found that more than two thirds (69%) of respondents to its carers survey said they had noticed no difference since the Act came into force, and ‘expressed frustration and anger at the lack of support they received in their caring role’. 65% were unaware of their rights and 65% had not received an assessment. 34% felt that their carer’s assessment was not helpful, and 37% had not received a letter or support plan after assessment.[7]

Local authorities saw £4.6 billion taken out of adult social care between 2010 and 2015.[8] Services, including those for carers, have suffered as a result. It is reassuring that research by the Association of Directors of Adult Social Services (ADASS) shows that, this year, only 1% of councils are targeting services for carers as an area for service reductions in 2016/17.[9] However, we have seen cuts to carers services, standstill budgets and extra charges introduced across local authorities in recent years. without a sufficient and sustainable funding settlement for social care, local authorities will struggle to increase and improve on their practice in this area, and carers will continue to lose out as a result.

Support and services don’t match needs

Some carers reported that support and services from both statutory and voluntary sources didn’t match their needs. This might be because of the type of activity available, or the carer’s ability to take advantage of what’s on offer. In some cases, there was a lack of awareness of what was on offer as well.

> *Whilst my [local] Carers Support team provide support and activities for carers, these are never suitable for someone in their 40s. Carer support events include bingo, singing, cookery sessions, theatre trips, pub lunches. These things don’t suit me. I’m not retired. I’m looking for more mindfulness, yoga, coffees out with friends.*
>
> MND Association volunteer feedback
>
> *Some cash to participate in an activity of my choice. Completely irrelevant.*
>
> *[I was offered] breaks but they could not be planned in advance.*
>
> MND Association Carers Survey 2015 respondents
>
> *In a lot of areas statutory services have no idea what’s available in the local area.*
>
> *Carers organisations, pamphlets – there is a lot out there but you’re too exhausted.*
>
> Focus group participants

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[7] Carers Trust, *Care Act for carers: one year on* (2016)
[8] ADASS, *Budget Survey 2015: key messages* (2015)
[9] ADASS, *ADASS Budget Survey 2016* (2016)

> *The local MND branch has a carers group which I've found very helpful in the past. I'm finding that because of our unique position [of living with a slower progressing form of MND] that – different people go to the group at different times [in the MND journey], you don't know if people will be able to relate to your position. Often it's people who are caring for someone who's newly diagnosed. Then I go into the position of supporting them. No one's going to know where I'm coming from because that's not their situation.*
>
> Telephone interview 1

> *At one point when I was getting so little support I contacted the carers association, and got heap of things about tea parties - I wasn't able to leave the house let alone go to a tea party.*
>
> Telephone interview 3

The overwhelming sense from participants is that support is occasional, ad hoc and often insufficient. There is often no follow-up at all after assessment and no sense of continuity in services for carers.

Support for carers needs to be appropriate to their age, circumstances and interests. If a carer is unable to fulfil wellbeing outcomes as a result of providing 24-hour care, a grant or voucher will not offer them any support unless that carer feels able to leave the person they are caring for. Local services should work in partnership with carers to develop their offers and to ensure that they are appropriate and sufficient for carers needs.

Real problems with respite care

Carers of people with MND repeatedly highlighted problems with access to respite care.

In some cases carers don't feel able to access respite care because of concerns about quality and expertise in caring for someone with MND.

> *Respite care – it can be so distressing for the person with MND that the carer will never leave their side again.*
>
> *The overriding thing that carers need is a break, but we don't see how that can happen – there is too much guilt, lack of confidence [in quality of service], communication issues [for the person with MND].*
>
> Focus group participants

Concerns about quality of care are discussed in more detail in section 3.2.

For lots of carers there are systemic problems with accessing respite care, or accessing respite that is proportionate to the level of care they provide.

> *There are resource limitations for respite care, slots at hospices, it's definitely a problem. There are quite often discussions in the [carers support] group about this.*
>
> *The only thing missing for me is respite care.*
>
> *Give me a break from caring.*
>
> *[I need] financial support for helping to pay for carers for respite or a regular help to take the emotional and financial pressure off the families.*
>
> *I have had to battle for 11 years with caring for my partner. I am mentally and physically tired, I have had one week's respite and that was last year. I have been told by my social worker that there is no respite available.*
>
> MND Association Carers Survey 2015 respondents

> *I had very little respite care – two hours to go out to do the grocery shopping. With long term disabilities there's time to set up respite care – with MND there was never the time or the feasibility for respite care.*
>
> Telephone interview 3

The MND Association Carers Survey 2015 showed that almost half (46%) of MND carers don't take planned breaks from caring, but that 59% of these carers wish they could. Of those that are able to take planned breaks, 42% rely on friends and family members to do so.

Carers were asked their reasons for not taking planned breaks. A significant number said that they did not want to spend any time away from their loved one. Several talked about the duty they felt towards their husband or wife, and the desire to spend as much time as possible with them before they died.

Others did not take planned breaks because the disease was at an early stage, so they were still able to work or take part in holidays and other activities with the person they were caring for. Some mentioned that they may need to take breaks in the future, as the disease progresses. It is vital for this very reason that carers of people with MND receive regular re-assessments and that support plans take into account future needs for support as well as current.

For others, however, taking a break was not an option because the person they were caring for was not willing to be cared for by anyone else, because of availability of care or fears about the lack of expertise held by care professionals.

> *If I am away from him, he gets very anxious and I worry so much I don't think I could enjoy any breaks for more than a few hours.*

> *I wasn't able to leave my husband's side, particularly over the last 2.5 years of his life. He would have been so frightened, wouldn't have slept and in the long run would have been more work for me on return.*
>
> *I cared for him with no help, did ask once but they never rang back so just did what I had to do.*
>
> *Not sure what is offered or [what] it entails.*
>
> MND Association Carers Survey 2015 respondents

Anecdotally, we hear about problems with availability of and access to respite care from across the country. We are extremely concerned that this service, which can be so important to supporting carers to continue their role, is not receiving sufficient funding to offer a real service to carers of people with MND.

Respite care and carers' breaks must be available at the right time for carers. Respite must offer sufficient and regular support to carers providing substantial levels of care, and must be delivered by high quality services with the right expertise to care for people with complex diseases like MND. Where people with MND are unwilling or unable to receive respite in a residential setting, care must be available at home.

MND, caring and young people

Participants told us that living with MND can have a significant impact on children and young people who may witness the progression of the disease, or may provide different levels of care and support for their parents, grandparents and other friends and relatives.

> *I am 18, it's very difficult trying to study for my A levels, keep up with my friends and look after my dad and help my mum look after him too. I feel a lot of responsibility and think a lot about things that wouldn't even cross my friends' minds.*
>
> *I have had to teach my young children to be more independent at an early age. I have had to teach them how to care for someone who is terminally ill and support them on their emotional journey. I have had to ask them to help me. I had had to deal with the emotional stress of being a mum who can't do everything she wanted to do with her children.*
>
> *It is hard to get a correct balance of life for us. When to ask them for help and when not. There are times that our girls have helped and seen, where as young adults they should not have but what is the alternative.*
>
> MND Association Carers Survey 2015 respondents

> *The Carers Strategy needs to incorporate young carers, it needs to be embedded. It's got to be about everyone involved, the whole family. Young carers are still hidden – schools aren't picking them up. Support*

> *and identification is variable. In [one area] there are schools that say there are no young carers, but we know there are.*
>
> *Families don't know about free school meals, the pupil premium, discretionary funds – we need to raise awareness but statutory organisations need to know what's out there. In a lot of areas they have no idea.*
>
> Focus group participant

Where children and young people are involved in caring, whether they are providing physical or emotional support, there needs to be a consistent application of duties under the Children and Families Act 2014. Those identifying and assessing the needs of adult carers must be aware of children and young people in the household and how living with MND might affect their wellbeing. Statutory services, including those not directly involved in supporting children and young people, need to be aware of available support and signpost to the right place to ensure young carers get the help they need.

Carers Trust is campaigning to put young carers on the map. It is gathering information about what local councils are doing to identify young carers and ensure they are aware of their rights. The map, along with information about what local authorities are doing, is available here: https://carers.org/putting-young-adult-carers-map

Support for carers after bereavement

Participants have told us that support for carers after the person they are caring for has died is often extremely limited, or even lacking completely. After fulfilling such a demanding caring role, this can have a profound impact on carers.

Some carers told us they received no support after bereavement:

> *When she died I was dropped, left. No one asked about me.*
>
> *[When they're alive] you're standing on a cliff edge. Where do you go after? The house is empty, services stop. There's no joined up working. You don't know what's next. It's scary for a carer.*
>
> *The person died and the very next thing that happened was a council tax bill. There's no sensitivity. Everything stops, all the money stops.*
>
> Focus group participants
>
> *My GPs never even acknowledged or said I'm sorry your husband's passed. Whereas the consultant neurologist who is incredibly busy wrote me a letter saying 'I'm sorry, he was a lovely man'.*
>
> Telephone interview 2

> *Absolutely no support [after he died]. The district nurses didn't come round until I phoned them.*

Telephone interview 3

Others felt that support did not come at the right time, or was not sufficient:

> *My daughter is sick now and it's two years [after bereavement]. I think that's a direct result of losing her Grandad, Grandma and Dad in the space of 18 months.*
>
> *It's all about timeframes, but people don't fit into them. Take special consideration for exams – the rule is within 6 months [of bereavement], but the grief process can be different with a long-term illness, there's no consideration of that.*
>
> *There are Mind counselling sessions but they're not specifically bereavement. There's Cruse but there are massive waiting lists.*
>
> *That period can go on for years when you lose someone to MND, it can be very long and very deep.*

Focus group participants

> *There was Cruse, it took a while but I went there. But you only get 6 sessions – I don't think that's enough. it takes six sessions to get to know someone and feel like you can talk to them. He wrote me a letter after and said I hope you're ok. He was very nice. But they've got a queue of people waiting too.*

Telephone interview 2

> *10 sessions [of counselling] was all I got. And it's the same [offer] for whatever [the situation] it is. It took six months for me to get that.*

Telephone interview 4

Evidence from MND carers suggest that this is a significant gap in service provision, and one which needs addressing urgently. Services stop and often there is no follow-up from health and social care professionals. Carers reported difficulties in getting items of equipment collected after the person with MND had died, as well as concerns around finances which will be discussed in more detail in section 4.

We back the call by Carers UK for a new programme of work around support for former carers, including pre- and post-bereavement and with finances and work.[10] It is vital that the experience of people caring for people with a terminal illness is recognised and valued, and that they are supported accordingly after the person dies. All health and social care professionals involved in the care of

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[10] Carers UK, *National Carers Strategy: top dozen asks* (2016)

the person with a terminal illness have a role to play in supporting carers through this period to make the transition as easy as possible.

3.2 Supporting MND carers to provide and arrange care

Throughout the research period, carers told us that the care and support for the people they were caring for was not adequate, and that this had a substantial knock-on effect on their own health and wellbeing.

Some carers felt that they were left to provide care without the right knowledge of available services or training to perform tasks.

> *There is no training whatsoever. You are just left.*
>
> *It drops onto you to do all the administration – DLA, facilities grants – and you've no prior experience. You start from nothing. And then you have to fight for it, then you have to appeal – we had to go to an appeals court for DLA. You don't have time, you don't have experience, you don't want to be there, you don't ever want to go back there.*
>
> *Even things like Continuing Healthcare, people in the most dire circumstances don't know about it.*
>
> *I had no idea how we were going to manage as it went on. No one told me about Continuing Care.*
>
> Focus group participants

> *I have a whole folder full of contacts that I've built up over the years. If you are in the early stages you don't know where to go.*
>
> Telephone interview 1

> *I look back on my time caring for my wife and question well over 50% of what I did and how / why / when I did it. It was pretty much blind instinct at the time, and time seemed to pass by so quickly, it was a major battle trying to stay a step ahead of [her] changing condition.*
>
> MND Association Carers Survey 2015 respondent

Others described care that simply wasn't good enough:

> *A care agency came in. An agency carer said to the person with MND 'I don't know why anyone listens to you, you'll be dead soon'.*
>
> *They were dealing with very complex needs and they were a generic service. It's the same with residential care – it's not able to meet those specialist needs.*
>
> Focus group participants

- *District nurse angry because person with MND wanted a shower on a Friday.*
- *Agency nurses arriving at midnight and not knowing what MND is?*
- *Agency nurses not understanding MND – dangerous!*
- *People with MND ignored in A&E – no eye contact, speaking to relatives only.*
- *Person with MND admitted to ward. Wife encouraged to go home for a rest. On return person with MND very distressed, unkempt. Nurse said ‘I couldn’t understand him’.*
- *Co-ordination.*

Focus group participants’ written responses to question: “What’s not worked?”

> *Paid carers were here for my partner and we didn’t feel comfortable with their couldn’t care less attitude.*
>
> *I had helpers come and help but I spent time clearing up after them as they always seemed to be in a rush, I think they had too much work to do this job properly.*

MND Association Carers Survey 2015 respondents

Some carers said that care wasn’t quick enough, or didn’t take into account the progressive nature of MND.

> *Even where there is a little bit better service, it’s not quick enough.*
>
> *Lack of ability of services to respond quickly to deteriorating situation.*

Focus group participants

> *By far the biggest problem we have is that all the professional support... [is] all reactive. There is nobody apart from me that is thinking ahead and anticipating future need and support requirements. Forward planning is essential because of the enormous delay in arranging the necessary support.*

MND Association Carers Survey 2015 respondent

> *The other thing is with MND the speed of getting assessed and getting the support as soon as possible because if it is the usual trajectory [is crucial]. I have spoken to carers distraught because literally on Monday the person needed something then by the following Thursday that need was no more. They’ll be dragging them from the bed to the chair because they can’t use that hoist anymore because the need has progressed so they can’t use it. I can imagine the feeling of panic. I have it some times when the need changes. That happens to us every few months maybe.*

Telephone interview 1

> *He had a week in hospital in June, was diagnosed in August, dead by November. He went down every day – from walking to using a stick,*

> *then no time at all from stick to wheelchair, he couldn't stand at all, it would take a couple of us to get him onto the toilet, he couldn't do anything... [Services were] beyond useless, just so slow, by the time they'd get you something – well, it took about six weeks to get a leg brace sorted out, he was past it by then.*

Telephone interview 2

Carers told us they felt that they often weren't listened to or respected as a partner in planning and delivering care. One focus group talked about this as a particular problem when a person with MND is admitted to hospital, where they felt it was very difficult to communicate what the person with MND needed and wanted to healthcare professionals.

> *As the carer you are also the bottom of the heap when dealing with healthcare professionals. Even when I'm doing "my job" getting [him] the best care I am made to feel like an annoyance or a pain in the arse. There isn't generally the respect there. What can I possibly know?*

MND Association volunteer and current carer

Carers also talked about the need to work in an integrated, joined up way. They described examples of good practice including partnership working between district nurses and multi-disciplinary teams involving a range of professionals. Many also praised the services of local hospices, which were able to provide high quality care at crucial points of the disease progression.

Good practice in care for people with MND, which involves carers in the planning and delivery, and takes into account the changing nature of the disease is not being consistently delivered. This leaves carers with the feeling of not being listened to. It also leaves them and the people they are caring for without the support they need to live in comfort and dignity and manage their progressive condition.

Researching support for MND Carers

Rosie Martin is an MSc Health Psychology student at the University of Central Lancashire. She has been researching the experiences of carers of people with MND and the support they receive during caring.

Her research with current and former carers has highlighted a number of common themes:

- Caring for someone with MND can be an intense and exhausting experience. For some carers it involves providing constant mental, physical and emotional care
- Carers have to be proactive in order to get services in place. They don't always know what is available or who to go to in order to get care and support organised. Support for carers may be out there, but it is the carers themselves who have to go out and find it
- Carers for people with MND have different relationships with work; some are forced to give up work because of their caring role. Others

3.3 What support do MND carers want?

During focus groups we asked carers what information and support carers should get to make their experience of caring better. Responses relating to care and support are collected in the tables below. Responses relating to benefits and finances are discussed in section 4.

Table 1: focus group responses – information and advice (care and support)

Information and advice
What do carers need to know?
• An information sheet on what services are available and how to access these in their area • Opportunity to speak to others in a similar situation • Awareness of the right to a carers assessment, how and who to ask for one • Information and advice must come at the right time for carers – not necessarily at point of diagnosis. • Basic information about the disease then ask what they want to know – everybody is different. • Provide information on key contacts. • Pace information giving according to need. • Carers need a list of help and information soon after being told they have MND. • What people to contact for help. What people will contact them to advise. How to get help in time, before illness deteriorates. • Carer's assessment – specific training needs being met. • Carers need to know what may be ahead for them. Immediately not that appropriate as it takes a while to absorb diagnosis. • How to use medical equipment needed i.e. cough assist etc. Who to contact out of hours if equipment breaks down. • Needs to be a general strategy whereby carers can access, and more importantly, be made aware of, the services available to them. This should be done immediately following diagnosis. • Specialisms – [eg] Occupational Therapists • Need a supporter who understands e.g. Association Visitor • 'Back-up' carer support available • Different roles of therapists and who to contact. Maybe similar to a care pathway [for MND] when different things arise
Who should tell them?
• GPs could be first to spot a situation where someone is in a caring role. Followed by the consultant that diagnoses the disease • For MND this should then flag to Clinical lead in the area, the Association and perhaps carer support groups to ensure that all available support is being offered • [MND Association] Visitors might spot other people in the family providing care whom the GP and consultant do not see. Association Visitors can direct them to sources of support they might miss and discuss with the [MND Association regional care development

adviser] about particular methods of support they might feel is required. • Every MND person and carer should have a named person i.e. care manager who is experienced in MND who would be point of contact plus deputy for holidays, sickness etc. • Information and advice must always be free and separate from services that carers may be expected to pay for in the future. • Each commissioning group should have a carers department with a team and each carer a designated team member. • Local councils need to be up to date on where adapted housing is, and how many are empty. • Health professionals need to be more aware of MND and neurological conditions more generally – education needed. • Should be a specialised nurse/neurological conditions coordinator in each region. Eg none in North Devon • Government leaflets • Local authorities • NHS • MND Association • Ideally – government • Realistically – other carers • Care coordinator • GP Surgeries • Early signposting to support services for carers and brief ‘what to do next’ at the point of diagnosis. • The neuroconsultant, MND coordinator/Care Centre to provide initial info and follow up after short while then the above and neuro/MND multi-disciplinary team and AV (plus signposting). • Care manager or possibly AV could point them in right direction and then appropriate person could contact person with MND and their carer. • Charities • Hospice • Hospital • Can’t rely on one source or occasion • Difficult to say as everyone is different. Every point of contact is important.

Table 2: focus group responses – support from local and national services (care and support)

Support from local and national services
Support to be a carer
• Patient/carer advocates – working independently of local authority/social services/NHS/welfare – who have authenticity (a bit like a regulator – CQC/Ofcom etc).

- Quick and easy referral for all carers [including] GP for – local support and carers assessments. More awareness among GPs to achieve this.
- From outset should have carers assessment and regular review.
- Facilitate introduction to support of whatever kind needed.
- Local MND branches to run carers meetings to exchange information
- Carers should be graded (use/develop an algorithm) and helped according to need. MND carers would probably score very highly.
- Training
- Advice
- Expertise
- Strategy must incorporate health and wellbeing of carers themselves – needs to be support for them during and after care takes place
- Peer group support
- Support groups
- Coordinated community clinical lead – a one stop shop for all needs so that they only have to make one call
- Home-centred multi-disciplinary team discussions which leads to a care plan
- Consultants and specialist nurses to help carer feel part of the process throughout
- Respite – even for short periods of time to allow own appointments, shopping etc
- Workshops to pre-warn a carer what may happen in the future e.g. feeding tubes (meet other carers too)
- Carers to be listened to by [health and social care professionals] as they probably know more about the people living with MND – can be very frustrating
- 6 week courses for carers to go to i.e. each week on a different session. Also carer makes friends with other carers.
- Help for carer in A&E/acute setting so when ‘trapped’ in hospital – carer can deal with medics/advocate for loved one. One idea – family liaison person
- MND Carers online module
- Carers grants
- Respite breaks
- Carers NEED A BREAK!
- Making what is available locally known to carers
- Understanding the frustration of being a carer
- Carers assessment should automatically trigger a whole family approach and a family assessment
- Access to respite care – makes such a difference if people can get a break, and know they can get a break. Helps them manage the road ahead.

Support for life outside caring

- Respite care to allow them to maintain independence
- Financial support to allow hobbies/breaks etc

• Signpost to places of leisure where carer has free admission to help with costs of leisure activities that they want to do with the person they are caring for • Signpost to advice about accessible places to visit – carers and person with MND might want to keep similar interests together • Signposts to organisations which will find a volunteer to support the person with MND to maintain their interests whilst the carer maintains their possibly different interests • Respite care • It is essential that carers have some time off and time to enjoy a hobby or interest outside of the home environment. Sitters/professional to look after person with MND. Hospice can help with day care. • Local community groups. • Trusted respite care i.e. hospices that know MND • Make known what is available and how to access provision • Socials that provide care too • Diary, pocket of activities to tap into.
Support after caring ends
• Contact and membership of support groups should be maintained • Is the carer in a position to help others? • Develop alliances with other carer support groups/bereavement charities • [MND Association] branches and groups reaching out to bereaved carers regularly so not felt forgotten • Emotional support • Bereavement support • Bereavement – something in place, delivered quickly and as needed. Probably onus on GPs to have face to face within 21 days of death. • Health and social care professional and Association Visitor: offer ongoing support – i.e. talk and signpost/facilitate access to specialist help eg grief counselling, psych services etc. • Local groups for bereaved carers to offer each other support. • At present Association Visitor continues contact and encourage to attend branch meetings, however pressure on Association Visitor this is difficult to continue • Good bereavement care – where they can find it – helping others who are carers e.g. sharing • Support and understanding by the authorities • Non existent

There are a number of common themes within these responses:

- Information needs to come at the right time, at the right pace and should be accessible from all professionals involved in providing care and support for people with MND

- Carers need information about what services are available and key local contacts, both for support for themselves and care for the person they are caring for
- Carers need information, training and guidance about how to perform key care duties safely
- Volunteers and peer support could have a key role to play in supporting carers and signposting to services for carers, both while they are caring and after their caring role ends.
- Respite care and carers breaks are a high priority both for supporting the carer to remain in their caring role and to help them maintain a life outside of caring.
- Bereavement care needs to be in place and ongoing; currently it is not.

Carers also came up with a number of specific suggestions for services and improvements that could be made. These include:

- Having a carer or family liaison officer in hospitals to ensure that the carer is supported and listened to when the person they are caring for is admitted
- Producing an information sheet for carers and people with MND explaining key services available and key local contacts
- Creating local-level carers' departments, where carers could access a designated single point of contact with the full range of information necessary to help them in their caring role

There are some examples of good practice in these areas around the country, often led by local carers services and associations. However, services aren't always consistent or visible to carers.

3.4 Our recommendation:

Create a universal offer of free, non-means tested support for carers while performing their caring role and after bereavement

It is clear from the evidence gathered for this report that support for carers needs to be improved in a number of areas. There is a lack of consistency in practice and availability across the country and many carers simply do without.

Carers contribute £132 billion worth of unpaid care each year. Just one carer providing 100 hours of care per week to someone with MND saves the state more than £89,000 per year. It is vital that they receive the right support to make sure they are able to continue their caring role.

In order to enable this, we call on the Government to:

- Allocate sufficient and sustainable funding to the social care system to enable local authorities and partners to deliver a high-quality package of support to carers
- Conduct a review into the availability, quality and range of respite care and support available across the country, and establish a clear programme for improving access to this

- Create a new programme of work around support for bereaved carers, including young carers, and ensure that post-bereavement support is timely, sensitive and sufficient. It must take into account the impact of caring for a loved one with a progressive and terminal illness like MND
- Encourage local authorities and voluntary and community services to ensure that carers have the right information about support available, both for themselves and the people they care for. Encourage the use of information packs providing basic information on key services and key named local points of contacts for carers and the people they care for
- Work with professionals who have regular contact with carers, such as GPs, hospital specialists, social workers and education and training professionals so that they are equipped to recognise and identify ways to meet the needs of the carer. This could include having a carer's passport that would help to identify carers and make sure they got the right support.
- Ensure that services and professionals take practical steps to comply with the Care Act 2014 duty of cooperation and work in partnership to identify and jointly support carers
- Create a statutory duty for the NHS to identify carers and promote their health and well-being, ensuring that they put carers needs at the centre of their work
- Ensure every carer is aware of their right to a carer's assessment to help identify and meet their support needs
- Ensure that assessments are offered consistently across the country to all carers. A carers assessment should take place in a timely manner, and must be repeated with follow-up assessments as needs change. Carers plans must take into account future as well as current needs
- Work with local services to develop a programme of accredited training for carers, including young carers, in key tasks and skills involved in delivering care
- Fast track assessments and provision of services for people who care for those with progressive and terminal illnesses
- Promote the role of carers as 'experts' in planning and delivering care for people with MND, including in emergency and acute settings. Encourage hospital trusts to provide and promote carer champions or liaison officers to ensure carers are supported and listened to.

4. Work, financial support and the cost of caring

Respondents to the 2015 Carers Survey are at different points in their working life:

- 56% are retired
- 12% are in part-time work, while a further 12% are in full-time work
- 30% are not in work because of their caring responsibilities.

The caring role can have a profound impact on people's finances and their ability to work. Often carers do not receive sufficient financial support to manage. Some carers also find it difficult to return to work after their caring role ends.

Conversely, some carers tell us that staying in work, even with reduced hours, represents a vital lifeline for them. Work can act as a form of respite, and can help carers to maintain their identity outside of caring.

This section discusses what carers tell us about the financial impact of caring, the financial support available and carers' experience of work, as well as what extra support MND carers need.

4.1 The financial impact of caring

A recent report by Carers UK and Age UK described the 'financial scarring' effect that caring can have on a person's resources. The report finds that carers tend to have lower earnings as a result of having to leave work, reduce hours or pass up opportunities. Carers can also face difficulties returning to work. They will face additional costs such as travel, household expenses, care costs and extra accommodation costs. Carers will have significantly lower levels of private pension saving than the rest of the population, lower levels of long term savings and will need to draw on their existing savings more to meet the costs of care.[11]

Carers of people with MND tell us that they face all of these problems. According to the 2015 Carers Survey, one third of MND carers are worried about money, and a quarter are worried about losing their job or their ability to earn. The personal story on the following page describes these challenges in more detail.

There is a serious mismatch between the economic contribution of a carer and the financial pressures they face. Just one carer for someone with MND providing at least 100 hours of care per week delivers savings to the state of at least £89,440 per year.[12] Despite this, carers are left trying to manage a precarious financial situation, often with little financial support.

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[11] Carers UK and Age UK, Walking the tightrope: the challenges of combining work and care in later life (2016)

[12] Calculated based on methodology from Carers UK, *Valuing carers 2015*: unit cost of replacement care (£17.20) x 100 hours x 52 weeks.

Personal story: caring costs
At the moment we're not badly off but the only reason is because we have some savings. My salary and his pension come together and we try as best we can to manage on that, but usually we dip into our savings, which come from the lump sum he got when he medically retired. My salary has come down considerably since I've had to curtail my hours in work and I certainly wouldn't be able to live on my salary alone. Also I have had to bow out of opportunities in work that have presented themselves because I can no longer focus on my career. It's not just the finances that suffer, it's career too. Those chances won't come again.

We can't afford to put anything into savings now so it's just getting whittled away. Other people are in worse circumstances. When you have to cut back on your hours, or the person has to stop working and accept a pretty measly salary [in the form of benefits], things get very tight. Other carers say they just cut back on other things – one told me she can't afford to get a hair cut. I do feel slightly panic-stricken when I have to take a lot out of the savings for something and know it's not going to be replaced, and how long will he live for, and what am I going to live on when he's gone?

Telephone interview 1

4.2 Carer's Allowance: not fit for purpose

Carer's Allowance gives carers who provide at least 35 hours of care and earn no more than £110 per week up to £62.10 each week in financial support. People in receipt of state pension may receive a 'top up' payment if their pension is less than the value of Carer's Allowance. If it is more, then they will not be entitled to the benefit, although may be able to get increased amounts of other means-tested benefits such as pension credit.

Our 2015 Carers Survey showed that almost two thirds of MND carers (54%) don't receive any benefits or allowances. 27% received Carer's Allowance.

Focus group participants felt strongly that carers of people with MND needed to be better informed about the benefits they might be entitled to, including Carer's Allowance. They also felt that Carer's Allowance needed to be better. There were problems with Carer's Allowance stopping when a person with MND went into hospital for four weeks despite the carer still being in a caring role, financial assistance ending too soon after bereavement, and being insufficient to pay for bereavement support and services. One current carer also talked about the frustrating process of renewing their claim each year:

> *I particularly resent the letter I get every April from [the Department of Work and Pensions] that gives me 7 working days to submit minutely changed figures (associated earnings I have) to allow me to re qualify for my Carer's Allowance. There is no exception, no understanding that*

> *you may not have the time to do this and you have to do it manually. That would be a great place for government to start supporting me*
>
> MND Association volunteer and current carer

Carer's Allowance is the lowest value benefit of its kind. Jobseekers Allowance (JSA), by comparison, is £73.10 per week for single adults aged over 25. While people on JSA could in many cases be expected to move back into work after a short period of time, people can rely on Carer's Allowance for many years, without any prospect of returning to work while their caring role continues. The table below shows the percentage of claimants in receipt of Carer's Allowance according to duration of claim as of November 2015.

Table 3: duration of Carer's Allowance awards in payment, November 2015[13]

	Total	**Up to 3 months**	**3 months up to 6 months**	**6 months up to 1 year**	**1 year and up to 2 years**	**2 years and up to 5 years**	**5 years and over**
	Caseload (thousands)						
Nov-15	768.68	30.73	41.87	76.54	119.62	216.88	283.04
% of total claimants	100%	4.00	5.45	9.96	15.56	28.21	36.82

More than a third of claimants have been in receipt of the benefit for five years or more. Given the cost pressures described in the previous section, the substantial financial contribution unpaid carers deliver and the significant barriers to moving back into work while still performing a caring role, it seems impossible to justify this low level of benefit.

Carer's Allowance needs serious reform to make it work better for carers. Its value must increase to at least the level of JSA in order to provide a better level of support for carers who cannot work. The earnings threshold must be realistic, and must rise in line with average household earnings figures from year to year. It must provide better support after bereavement, and for longer.

There must also be a mechanism, such as an earnings taper, whereby carers who are able to do some work are still able to top up their income through Carer's Allowance. A taper would help carers of people with MND to reduce their working hours and receive the necessary financial support as the person's disease progresses and their own caring role intensifies.

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[13] Data from Department for Work and Pensions, '[Carer's Allowance - cases in payment Caseload (Thousands) : Time Series by Duration of current claim (days)]', *Tabulation Tool* (accessed 28/07/16)

Personal story: caring and Carer's Allowance

If you had met me a few years ago you would have been talking to a secondary teacher, running her own subject department. That was a very hard job with long hours. But today, you see me here in my role as Mark's carer and this is the hardest job I've ever done.

As I easily cared for Mark over 35 hours a week I was told I could apply for Carer's Allowance. Filling in the complex forms took time and I had additional supplementary ones to fill in. I had to ask an accountant friend what they wanted to know, as even I wasn't sure. Eventually I was back dated my claim by three months. When there was a slight change in my financial circumstances I had to fill in all of the forms again; with a ridiculously short turn round time; again I have to ask for help.

Claiming carer's allowance makes me feel that someone values the work I do now. The money helps me be able to care and spend time with my husband.

I used to earn £150 a day. £63.10 a week means more to me now but I can't increase this amount. I can't use my savings again, or create more savings. I've used them up. I often think that having the disease is bad enough but living with the consequences of the enforced loss of income is worse. I only have 20 years of employment so my work pension is frozen a minimum NI contribution is made via my carer's allowance claim.

It allows us to volunteer and advocate on behalf of others. To come here today to speak and tell you what its like to live with MND and Kennedy's. It gives us purpose and improves our quality of life and helps makes sense of something we can't make sense of.

Excerpts from speech at the All Party Parliamentary Group on MND December 2015 meeting by Katy Styles, who cares for her husband Mark, living with Kennedy's Disease (a rare, genetic and slow progressing disease of the motor neurones)

4.3 Carers' experience of work

Carers repeatedly told us that, for those who were able to, work was an important source of continuity in the face of an ever-deteriorating illness and respite from the pressures of caring.

Personal story: caring and working

I still work part time. I'm usually at home for six days then work for three. I only recently recognised that at the end of those six days I feel pretty depressed and don't want to go into work. Then half way through my first day at work I'm back to myself. You get taken over by the caring role, defined by it; it takes away your sense of self. When I go into work that's when I'm being myself. Then you go back home and you go back into that same cycle.

What's helped me to stay in work – my employers have been very understanding. They very generously said choose your shift pattern on the rota. It's a nine day rolling rota – it's easier for a carer to do three days in a row, and they allowed me daytime shifts. We work as part of a team – you can go immediately at the end of your shift because there's someone to take over. You can't just ring and be late when you know the [paid] carer is leaving at 5pm. They know I'll always be back when I say I will be to take over caring.

They really have gone out of their way to make sure it suits me. I'll get shift cover for appointments if I give them enough notice, and the more help we have at home the more other things I can get involved in at work, but they'll always contact me in advance to make sure I can get that help in.

No exaggeration – it keeps me sane. If I was just at home I think it would just be too depressing and tiring.

Telephone interview 1

However, they also told us that there were problems with lack of flexibility from employers, and difficulties returning to work after bereavement, even where the person with MND had died relatively soon after diagnosis.

Carers asked employers to be more flexible in recognising and supporting their needs:

> *Need to encourage employers to be more sympathetic to carers – allow working from home or flexible working.*
>
> *Employers should keep jobs open for carers, they're not sympathetic enough.*

Focus Group Participants

For some, there was a lack of recognition of the skills that performing a caring role could bring.

> *The skillset of a carer – it's not recognised that it's the kind of things you could put on your CV. Prioritising, communication skills, arranging appointments.*
>
> *It's project management.*
>
> *Careers advice for young carers needs to think about the skillsets and broad range of career options for a former carer. Young carers have limited horizons. You need to help them reach their full potential – we don't guide them as we should.*

Focus Group Participants

The personal story below illustrates one of the barriers to returning to work that can be created by lack of recognition by employers of the caring role, and lack of sensitivity when working with or interviewing someone who has cared for a person with a terminal illness.

For others there was a clear role for Government in providing financial and other support that would enable a carer to stay in work in the longer term.

> *Statutory carers pay – that would allow someone to stay in work and keep up employer contributions, top up finances, contribute to National Insurance payments, etc.*
>
> *There needs to be a joined up package around benefits, entitlements, back to work support would also be useful. Involve the Jobcentre Plus?*
>
> ***What support do carers need?***

- *Information about their caring role for their employer and what support they might need*
- *Signpost to organisations which can advise carers on their rights at work*
- *Advice about getting back into employment if they have had to take a step away*
- *Possible financial assistance to put you back to a normal life*

Focus Group Participants

For many carers staying in work, where they are able to, is vitally important. For many others returning to work after bereavement is a crucial next step, and one that should recognise, value and be sensitive to their experiences. There is a clear role for Government to encourage employers to respect and support current and former carers, in order to benefit from their considerable skills and resilience.

There is also a role for Government in supporting people who need to take a break from working, or who need a more flexible working pattern. The statutory right to request flexible working, introduced in 2003 and extended in 2014, offers a useful means of helping carers to balance their job and caring responsibilities. However, Carers UK and Age UK suggest that there is a lack of awareness of this right, and a reluctance among some carers who are worried that making a request might harm their reputation and risk losing their job.[14] Carers who need a break from their employment because of their caring duties only have an entitlement to ‘reasonable time off’. However, as Carers UK and Age UK highlight, this is not a system that is well understood by carers or employers.[15] There is no statutory entitlement to carers leave in the UK. We believe that creating such an entitlement would give carers a greater level of security, and would help to normalise caring and carers in the workplace.

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[14] Carers UK and Age UK, Walking the tightrope: the challenges of combining work and care in later life (2016)
[15] Ibid.

Personal story: going back to work
After my dad died I went back to work [in financial services] far too quickly, I only lasted 5 weeks. I then had to take a little break, then found a new job for 3 months and they extended me for a further month. Then after that there were problems, people asking very uncomfortable and direct questions in interviews.

At first I tried to keep it very high level on my CV and LinkedIn profile - “caring for a sick relative” as I didn’t want to put off employers but I was getting lots of probing questions at interviews so I re-worded it to a parent, but this still didn’t stop the questions. So I amended again to say terminally ill parent thinking that people would make interviewers sympathetic and not say anything in interviews to make me feel more uncomfortable than I was, but I still had a number of very awkward interviews. One interview went really well and I definitely felt that it would progress to a second until the end when they said “I want to ask you about your gap - so your dad died then?” Then other questions – “how is your mum doing? How is your mum coping?” What added value is there to an interviewer to ask you that? I looked away, I didn’t want to look at them; I probably did look like I was lying because I thought I’m going to start crying during a job interview and my body language probably made me look very uncomfortable as I was trying so hard not to cry. I never heard back from them, not even the standard rejection email.

After that someone at an interview asked ‘so your dad died then?’, But people kept asking questions at other interviews. Then it got to a point where I was like - just ask me, I’ll be very direct about it. But I want to be asked about my skills and experience.

He died in November, then I had December off, so there’s a gap. Someone said to me ‘what were you doing in December?’ I said, “well it takes two and a half weeks to organise a funeral in this country”. I just got to a point where I thought I can’t have any more interviews like this. Now looking back I think it’s kind of comical even though it’s not. Eventually I found something again and started back two months ago.

Telephone interview 4

4.4 Our recommendation

Create a system of financial and employment support that ensures that carers do not experience hardship or poverty as a result of their caring role

Many carers will have to give up work or reduce their hours in order to care for someone. The extra costs of living with a disability, including paying for social care, home adaptations, transport and extra household costs, will compound an already fragile financial situation.

Carers must therefore receive adequate financial support in order to enable them to both continue their caring role and ensure that they are able to maintain a decent quality of life. Government should:

- Introduce a statutory entitlement to carers leave
- Provide a benefits system that offers sufficient financial support to carers who are unable to work at all, or who have to reduce their working hours, in order to care for someone, and that does not put pressure on them to return to work while providing high levels of care. This includes:
    - Increasing Carer’s Allowance to at least the same level as Jobseekers Allowance
    - Introducing a ‘taper’ system of support so that carers can vary their hours over time, or so they can gradually reduce their hours as the demands of caring increase and still get financial support
    - Look into how best to support carers in receipt of a state pension
- Create a benefits system that takes the pressures of caring full time into account, that is simple and clear to navigate and where processes such as renewing claims are as light-touch as possible
- Raise awareness of the existing statutory right to request flexible working and promote good practice in this area. Consider the creation of a kitemark or other accreditation system for employers that offer and promote flexible working to support carers
- Create information and guidance for employers about valuing and respecting carers and former carers. Identify and celebrate businesses that are carer champions
- Work with employers to ensure that when a carer is able to return to work, after their caring role ends, their role and experience is valued and the transition back into work is made as easy as possible.
- Create a comprehensive and specialist programme of back-to-work support for former carers that could be delivered by Jobcentre Plus staff with expertise in supporting carers
- Work with education and training professionals to ensure that young carers have consistent access to career guidance that recognises and values the skills they have acquired through caring
- Work with local services to develop a programme of accredited training for carers, including young carers, in key tasks and skills involved in delivering care

5. Recognising, valuing and celebrating carers

We asked focus groups what Government and other groups could do to better value and celebrate carers. The table below shows their responses.

Table 4: focus group ideas - valuing and celebrating carers

Valuing and celebrating carers
What can Government do?
• MPs/Government – speak up! (eg in debates.) Join APPG! Attend the right meetings. Listen. • Help financially • Support with working • Action what they learn in surveys • Acknowledge the amount of time etc they [carers] give • Provide networks on line – carers meetings • Government should consider giving Carer’s Allowance to carers who are drawing a state pension. The unpaid carer needs financial help. • Inclusion • Understanding • Listening • Would only be reasonable and compassionate to apply equivalent Inheritance Tax rules to unmarried/partner carers as per married (ie transfer of lifetime allowance) • Some sort of follow-up – has the carer adapted post-death – not just grief but have they recovered fully? • Promote better public understanding of the immense value to society of unpaid carers. • Government needs to hold local councils to account if not giving carers proper rights under the Care Act.
What can other groups do?
• [MND Association] support group facilitator – looking at this as a new core volunteering role • Carers peer support group • Look at finding some pilot ideas. Carers tell us repeatedly what they need but nothing changes. • Better training for agency nurses • Helplines • On line forums • Mentoring for carers • Need a campaign for better access to specialist replacement care so carers can take a break of their choosing • MND Association should work more together with Carers Trust and Carers UK • Local groups to work on relationships with carers centres to ensure MND carers can access these for services and to raise awareness of MND with carer support staff locally.

Participants also discussed the fact that young carers can sometimes feel particularly undervalued:

> *Children don't want it to be known [that they are carers]. They're embarrassed about it, maybe in denial. Good schools will be promoting young carers as amazing young people, there'll be drop-ins with the school nurse, young people will be self-identifying as a result.*
>
> *Young carers don't like the label 'young carers'.*
>
> *It's hard to be different in any way.*
>
> Focus group participant

As discussed at the beginning of this report, carers of people with MND can feel a huge sense of isolation, loneliness and loss of identity. Many of the recommendations throughout this report would help to make them feel recognised, valued and respected for the important role they provide, and go some way to reduce this feeling.

Carers told us that they didn't feel listened to, both as experts in MND and regarding consultations such as this.

> *Thing is, this is happening six times a day.*[16] *I asked this question 10 or 15 years ago – who cares for the carer?*
>
> *We've had these conversations before. Nothing ever changes.*
>
> *Not just listened to, it's got to be actioned.*
>
> Focus group participants

Participants very clearly felt that little changed when they took part in consultations about services, that their suggestions weren't adopted and that there was very limited feedback to them.

Peer support is very important to the carers we spoke to; the Government should promote this activity, and other voluntary and community groups should work to ensure that groups are available and easy to find at a local level.

5.1 Our recommendation:

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[16] On average six people are diagnosed with MND and six people are killed by the disease each day.

Work towards a society where recognising, valuing and supporting carers is everyone’s responsibility

Carers, just like anyone else, have a diverse range of experiences and interact with a wide range of professionals, organisations and communities. However, their distinct needs are not always met, and their role and experience is not always valued. Implementing recommendations throughout this report will help to show carers that they are recognised and valued. In addition, to encourage a better society for carers the Government should:

- Ensure that the new Carers Strategy includes measurable outcomes. Collect appropriate data and report on progress towards goals on a regular basis, in a way that is accessible to carers
- Create and promote a role for Carer Ambassadors to sit on national and local decision-making bodies, such as health and wellbeing boards, strategy groups and NHS advisory groups
- Share and promote good practice examples of peer support, and encourage and enable voluntary and community groups to ensure these are in place and visible to carers
- Encourage education and training providers to take best practice approaches to celebrating young carers
- Continue to create, promote and support initiatives that increase public understanding of carers’ contribution to society.

6. Conclusion

Carers of people with MND are not getting the support they need or deserve. The right kind of support is not being put in place quickly enough, and carers do not know where to look or who to ask for it. Assessments can be extremely helpful when they are done, but they are not done consistently, regularly or with a view to future care and support needs of both the person with MND and the carer. Respite care, a top priority for the carers we spoke to, is insufficient. Carers do not receive enough financial support and, while work can be incredibly valuable to them, they can find it difficult to return to work after bereavement. Post-bereavement care overall is not available at the right time, and often carers do not know about it at all.

These messages sum up what carers of people with MND tell us about the support they receive. This is not good enough.

Caring for someone with MND is an intense, lonely and demanding experience. Carers of people with MND are also proud to be carers; they see it as part of being a husband, wife, child, sibling, friend, and they want to spend as much of the remaining time with the person they are caring for as possible. However, the illness is terminal in all cases, and many carers will see their loved one deteriorate extremely rapidly. Carers talk about losing their own identity, just as the person with MND loses their ability to move, speak and do all the things they used to do.

Carers of people with MND must be better valued, celebrated and supported for the amazing care they provide and contribution they make to their loved-one's lives and society as a whole. The MND Association has a role to play in making sure that happens, as do services and employers, and so does Government. Government must lead services, employers and voluntary and community organisations in improving support for carers, and it must listen to MND carers.

Acknowledgements

Thank you to all carers, former carers, MND Association volunteers and staff who helped with this report and worked to promote the voice of MND carers.

List of evidence, interviews, focus groups and other material used to inform this report

- MND Association Carers Survey 2015
- Telephone interview 1 – current carer
- Telephone interview 2 – former carer
- Telephone interview 3 – former carer
- Telephone interview 4 – former carer
- London focus group (one volunteer, one staff member)
- North West Forum focus group (9 volunteers,6 staff members)
- South West focus group (12 volunteers, one staff member)
- Interview with Rosie Martin, MSc Health Psychology student at University of Central Lancashire
- Excerpts from speech at the APPG on MND December 2015 meeting by Katy Styles, who cares for her husband Mark, living with Kennedy's Disease
- Feedback from MND Association 'Campaigns Contact' volunteers regarding draft 'key asks'.

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